DOCUMENT RESUME

ED 452 661 EC 308 507

AUTHOR	Popper, Barbara K.; Hausslein, Evelyn
TITLE	"Who You Gonna Call?" [and] New Roles for Parents.
INSTITUTION	National Early Childhood Technical Assistance System, Chapel Hill, NC.; Federation for Children with Special Needs, Boston, MA.
SPONS AGENCY	Special Education Programs (ED/OSERS), Washington, DC. Early Education Program for Children with Disabilities.
PUB DATE	1994-00-00
NOTE	8p.; Published with "Coalition Quarterly." Theme issue.
CONTRACT	HS91011001
AVAILABLE FROM	National Early Childhood Technical Assistance System (NECTAS), 137 E. Franklin St., Suite 500, Chapel Hill, NC 27514-3628. Tel: 919-962-8426 (Voice); Tel: 877-574-3194 (TDD); Fax: 919-966-7463; e-mail: nectas@unc.edu; Web site: http://www.nectas.unc.edu.
PUB TYPE	Collected Works - Serials (022)
JOURNAL CIT	Early Childhood Bulletin; Spr-Sum 1994
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	*Agency Cooperation; Coordination; *Curriculum Development; *Disabilities; *Early Intervention; Parent Empowerment; *Parent Participation; Parent Teacher Cooperation; Partnerships in Education; Preschool Education; Professional Development; *Professional Training; Special Education; Staff Development; Training
IDENTIFIERS	Individuals with Disabilities Education Act Part C; *Interagency Coordinating Council

ABSTRACT

This special double issue of the "Early Childhood Bulletin" explores issues for parents who are members of Interagency Coordinating Councils (ICCs) for their states' early intervention programs. The first article discusses issues parents may want to consider before they assume new roles in their ICC and in related activities. It also highlights the results of a 1993 survey which shows that opportunities for parent participation at program and policy levels are increasing significantly. The second article discusses ways in which parents can foster parent/professional collaboration by participating in preservice and inservice training opportunities for professionals. References and a list of resources for assistance in developing a curriculum for training are included. (SG)

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"Who You Gonna Call?"
[and]
New Roles for Parents

Barbara K. Popper and Evelyn Hausslein

Early Childhood Bulletin
Spring-Summer 1994

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Coalition Quarterly

EARLY CHILDHOOD BULLETIN

News by and for Parents and Parent Members of State Interagency Coordinating Councils

Double Issue
Spring & Summer

Prepared by the Federation for Children with Special Needs
Parent Component Staff of NEC*TAS

1994

"WHO YOU GONNA CALL?"

By Barbara K. Popper
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Boston, Massachusetts

This special double issue begins to explore issues for parents on Interagency Coordinating Councils (ICCs) as they encounter opportunities to try new roles and activities. The first article, by Barbara Popper, discusses issues parents may want to consider before they assume new roles. It also highlights the results of a survey showing that opportunities for parent participation at program and policy levels are increasing. The second article, by Evelyn Hausslein, discusses parents as trainers. The third article, to be printed in the Fall issue, will discuss ways ICC parent members can gather and present information to best represent families.

A popular movie made that slogan familiar, but it is also familiar to many parents of children with disabilities and special health needs. Parents often are called upon to serve in capacities that go beyond representing the interests of their own family and child. They may be asked to collaborate with professionals in efforts to improve or redesign services, programs, and policies that impact many families. Committees, task forces, and program administrators may look to parents and family members to help guide their efforts to be more family centered. The parents receiving this Early Childhood Bulletin *are likely to be the ones called by other parents, community leaders, or professionals who are looking for parents to fulfill a variety of roles, from providers of information to serving as committee chairpersons.*

When parents become active in Interagency Coordinating Councils (ICCs) because of some interest in programs for their children, they take on a new public identity. They became known not just as "John's or Jane's parents," but as parents knowledgeable about or representing a particular disability or health condition or service need. That association often leads to invitations — and expectations — about other things that "John's or Jane's parents" might like to do.

Often parents do not need an invitation from another to become involved: Their own experiences compel them to action. One mother of a child with cardiac problems learned from a consumer group about a parent advisory council at the hospital where her child had surgery and was receiving ongoing care. She was eager to join the council so that she could learn more about the hospital and offer the administrators her suggestions for possible improvements. Her participation helped change specific hospital policies, such as sibling visitation hours; provided guidance on renovation decisions; and led to new and better ways of getting valuable feedback from parents on the care that was being provided. Other parents hear about pending legislation and feel that political involvement is the best way for them to help their own child as well as all the other children with similar conditions.

No matter what compels parents to contribute to these larger efforts or where they choose to devote their time, such activities inevitably bring parents into new arenas. As they become known and recognized as resources, available to share their views and their time with other parents and with professionals seeking consumer views, parents may find that they are being deluged with requests.

Here are some things to consider when deciding to participate. First, rather than agreeing immediately to take on new tasks or to represent families on a new committee or task force, ask how soon a reply is needed. Parents may wish to ask for more information about the purpose and time commitment involved and may wish to talk with others first, including their spouse, to see whether it fits in

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with other commitments. Using the time available before a response is needed to weigh the pros and cons can allow for a better decision than one made in haste. Volunteers have the luxury of picking and choosing only those activities that seem relevant to them or that offer them the chance to learn valuable information. They also learn to keep handy the names of other parents who might be interested in participating. Declining gracefully while offering a referral to another parent keeps the door open for other opportunities that might be of greater interest or that might come at a better time for the family.

Finding the "Right" Parent

Officers and board members of parent groups always are looking for others to share the workload and to help the organization be effective. High on their list of desired attributes are enthusiasm, a certain level of organization, and good communication skills. Parents who have a perspective gained from firsthand experience over time are essential, as are parents of younger children who lend a fresh viewpoint and new energy to the organization's efforts. In the same way, professionals see the value of bringing to their parent-professional collaborative activities the viewpoints of parents of young children, parents whose children are newly diagnosed, and parents who have already shown their leadership qualities through their own parent organization activities.

Different viewpoints exist about what characteristics are most important and about how to select parents to join with professionals on committees and on task forces. The range of viewpoints was crystallized for me while conducting a telephone survey of state health departments in 1987. The intent of the survey was to discover how state health department officials identified parents to serve as consumer representatives on their department advisory committees. I had just completed a call with one official who was clear that the best path was to find parents who were already active. These parents, he felt, would be comfortable in forums with professionals and would have gained some perspective about their own child's situation. Professionals would feel comfortable with parents who already knew some of the special terms and who had experience with committee work.

The next state health official I interviewed, who worked in a state contiguous to the first one, exclaimed, "Spare me the professional parents!" She preferred that only those "fresh from the experience" of either diagnosis or hospitalization be invited to participate. What was each official seeking and what was each hoping to avoid?

In many circles, the "professional parent" label is not meant as a compliment. The terms "active parent" or even "parent activist," by contrast, bring to mind other types of activists in our society championing such causes as civil rights and protecting the environment. The term "professional parent," however, implies a parent who has had lots of experience representing other parents, but who has lost touch with the day-to-day reality of other parents and the parenting experience. In an extreme expression of this point of view, one professional said that, in her opinion, after a few years of involvement a parent was not useful any more as a parent representative! Parents, of course, know that they gain valuable new perspectives from the many changes and challenges they and their children experience over time.

If professionals select only very active and involved parents with a proven ability to collaborate, how will new parents be considered for participation in the planning of policy and programs? Does the "professional parent" join the professionals in deciding what all parents need?

On the other hand, some professionals believe that parents of newly diagnosed children are in the best position to evaluate available services and programs. However, the newness and even shock of a diagnosis or experience of hospitalization needs to wear off before many parents are able to figure out what to do next about their own family's situation, let alone evaluate a program affecting many families.

How then can you find the right mixture and balance both for professionals seeking family input and for parents wishing to participate and wondering how they can best make a contribution that will be satisfying for themselves. Asking two questions may spur a dialogue between those asking for parent involvement and among parents

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seeking to become partners in improving programs and policies for families of children with special needs:

- Does the definition of the "right" parent depend on the length of time of involvement in activities and organizations or the level at which parents are ready to take on new commitments?
- Is the parent connected to other parents and parent organizations and interested in networking with parents?

How these questions are answered by the professionals will determine the success of attempts to establish stronger links and ties to families. The answers also will affect future opportunities for participation by a diverse group of parents.

Parent Participation in State Title V Programs

Many of the early successes in getting special education laws passed and in teaching parents about their rights was done by parents as volunteers. Gradually a few parent centers received U.S. Department of Education funds, and support for parent programs has grown over the years. As progress was being made to expand the role of parents in education, the Federation for Children with Special Needs was working simultaneously to bring about similar changes in health care. As one way to gauge change in this area, the Federation's CAPP National Parent Resource Center conducted a survey of state health departments' Directors of Divisions for Children with Special Health Care Needs to learn the degree to which parents were participating at program and policy levels in these departments (Wells, Anderson, & Popper, 1993). Since state health departments are critical collaborators in early intervention systems — often serving as lead agencies for Part H — the results of this survey have implications for parents serving on ICCs.

We asked about the extent to which family members were being included in committees of state health programs and whether or not any family members had been hired as staff or as consultants. We learned that almost every state had invited parents or other family members to become involved in committees, task forces, or as advisers in some fashion (50 of the 51 respondents — all but one of the 50 states and the District of Columbia — have parents on committees).

In addition to the questions about the nature and degree of parent involvement, the survey included questions about the benefits and the difficulties of having parents participate. Typical answers to the questions about the benefits of having parents participate on committees were that the parents enhanced the state's ability to carry out its mission, increased the understanding of family needs, improved planning, improved family/professional communication and increased the empowerment of family members. When responding to the questions about the difficulties of having families involved, state departments most often mentioned difficulties in finding suitable meeting times, long distances to meetings, lack of transportation, inability to find child care, and the unpredictability of children's health.

The survey then asked if states offer support for parent activities or to parent organizations. Of the 92% of states that offer support for parent activities or groups, 85% offered travel money for parents to attend meetings and conferences, 47% paid for child care for meeting times, and 38% paid parents for their time or services as advisers. Recognizing that families can donate some of their time, but will need some assistance with travel and child care, is becoming better supported.

The survey results are an important indication that the critical role for parents at program and policy levels is receiving more recognition. This recognition should lead to even greater opportunities for parent participation in a wide range of volunteer and paid capacities. The survey findings also indicate that families do value the opportunity to assume new roles, and often overcome many difficulties to participate.

Reference

Wells, N., Anderson, B., & Popper, B. (1993). *Families in program and policy: Report of a 1992 survey of family participation in state Title V programs for children with special health care needs.* Boston: Federation for Children with Special Needs. Copies may be obtained from the Federation at 95 Berkeley Street, Boston, MA 02116; (617) 482-2915.

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Here are some questions that may be useful in setting your own criteria and guidelines for participating in your ICC and in related activities:

1. **What have you decided are your own goals or reasons for accepting any new involvement offered? Does this new invitation fit in with your goals?**

   Goals: educating myself, getting to know the players, considering new career, advancing the goals I have for my child, making changes in the system

2. **What barriers to being able to fufill any new commitment do you see ahead?**

   Barriers: time limitations, scheduling hassles, child care arrangements, expenses of travel and parking, other family obligations

3. **What resources are being offered, or what can you request, to help you balance a new set of tasks with your other responsibilities?**

   Resources: money (stipend, salary, consulting fee), reimbursement of travel and parking costs, child care costs

4. **Who is available to help you learn more about the new expectations? Are formal orientation sessions provided? By whom?**

   Helpers: experienced parents, professional staff members, mentors

5. **How will you evaluate whether your efforts are being successful and whether the rewards continue to outweigh the difficulties?**

   Evaluation: personal checklist of goals for regular review

6. **What would convince you either to increase or cut back on your level of activity?**

   Reasons for Changing: success of efforts, feeling encouraged/ discouraged, comraderie, fatigue, family needs, children's activities, needs of parent group

7. **What plans have you made to help you pace yourself?**

   Pacing supports: answering machine, regular exercise and relaxing time, support of spouse, buying a filing cabinet

8. **Will you have opportunities to share your ideas and impressions with other parents, and perhaps be able to bring along a "partner parent" who also could substitute for you when you are unable to be available?**

   Being the only parent can be uncomfortable since we all know our experiences and opinions aren't representative of all families.

This Bulletin is prepared by the staff of the Federation for Children with Special Needs who participate in the National Early Childhood Technical Assistance System (NEC*TAS), which is funded through the U.S. Department of Education's Office for Special Education Programs (OSEP), Early Education Program for Children with Disabilities, under contract #HS-91-01-1001 awarded to the Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill. Grantees undertaking such projects under government sponsorship are encouraged to express their judgment in professional and technical matters. Points of view or opinions, therefore, do not necessarily represent the Education Department's position or policy.

Dear Readers,

This issue of *Early Childhood Bulletin* was originally sent to everyone on the NEC*TAS mailing list last August. Although the post office has verified that this mailing was sent, we understand that many of you never received it. We assume that it is lost somewhere, and so we have had it reprinted. We apologize for the delay. Thanks for your patience.

Janet Vohs, Editor

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New Roles for Parents

by Evelyn Hausslein
Early Childhood Specialist
Federation for Children with Special Needs

One of the principles of family-centered care set forth in the book Family-Centered Care for Children with Special Health Care Needs, *is "Facilitation of parent/professional collaboration at all levels: care of an individual child; program development, implementation, and evaluation; and policy formation" (Shelton, Jeppson, & Johnson. 1987, p. 71). Parents who are serving on Interagency Coordinating Councils (ICCs) for their state early intervention programs already are active in policy formation. Another important way for parents to foster parent/professional collaboration is by participating in preservice and inservice training opportunities for professionals. This article outlines some issues to consider in thinking about how parents can contribute most effectively to training and suggests some resources for assistance in developing a curriculum for training.*

The first questions parents must answer when asked to help with training are "What role am I being asked to play? Am I being asked to give advice on the contents of the curriculum, to participate in delivering the training, to review a curriculum from my perspective as a parent, or to observe a training session and evaluate the teaching style or the content?"

Sometimes a curriculum developed by teachers and trainers is offered to a few parents or a parent advisory board for review. The most important expertise you have to offer is your firsthand experience as a parent. Tell how the tone and approach impress you as a parent — useful, offensive, informative, etc. Give specific examples of how the proposed training would have helped or hindered the services and support given to your family; how it would have helped or hindered the providers who worked with you; and how it would have enhanced or discouraged your participation as an equal member of the planning team.

Review the curriculum from the perspective of whether or not it is consistent with and furthers the ideas of family-centered care. In addition to the principle of family participation mentioned in the introduction, it may be helpful to consider other principles cited in the same book:

- Is there a recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate?
- Is the view of families as equal partners and collaborators with professionals upheld?
- Are family strengths recognized and their individuality respected? (Shelton et al., 1987)

Participating in Training

While parents have much of value to contribute to the entire range of discussions about children with special needs, one of the most important contributions they can make is to add a context of reality to policy and program discussions. By telling the story of their child and family, parents can make abstract points memorable by adding the richness of real examples. If services are to be truly family centered, opportunities for professionals to learn directly from parents are critical. Families' stories, their firsthand experiences about what it is like to be a parent of a child with a disability and how the work of early intervention affects their family, focus the training on consumers, i.e., families. These stories help create a vision of *why*, not just how and what, services are provided.

To be most effective intelling your story, it is important to know the specific topic to be discussed and to think about the principles or issues you would like your story to illustrate. Once you have decided the issues within the topic area that are important to you and your family, craft your story by drawing on specific incidents that illustrate them. Talk about when things went well and what specifically made them go well, as well as when things did not go well and what you wish had been done differently. Be specific. To make your story come alive, bring along a picture of your family to pass around (or you can have an overhead transparency made of any photo at a copy store!).

As parents gain experience, many are asked to participate beyond telling their story. It is becom-

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ing more common for parents to join the faculty of programs and colleges providing trainings, modeling the partnership and collaboration that is the underlying philosophy of Part H. Now parents are developing and delivering curricula on a wide range of topics related to children with special needs. While they use their own and other families' stories to illustrate key points, there is a structured curriculum. When participating in this way, consider your experience as a parent coordinating your child's care and managing a household, as a member of your community, and as a person with work skills and knowledge.

You also may be invited to participate as an observer of the training. In this role you are not only a learner, but you also will give feedback to the trainers as to the usefulness and effectiveness of the training. Think about how the training did (or did not) promote a family-centered approach to support and services, and whether or not parents collaborated in the design and delivery of the presentation. In this role it is good to comment as specifically as possible on what was particularly good and what recommendations you would make for change. Did the audience have an opportunity to respond, to ask questions, and to contribute their own experiences? Was a parent participating in the training and was it clear as to the importance of the parent's contribution?

It is always important to remember that family-centered service delivery is a very new concept. While the principles are embodied in Part H legislation, they are far from being part of business as usual. New professionals seldom are taught these principles and their implications as part of their formal training; parents can contribute to their ongoing learning.

Reference

Shelton, T.L., Jeppson, E.S., & Johnson, B.H. (1987). *Family-centered care for children with special health care needs.* Washington, DC: Association for the Care of Children's Health.

Resource List

When asked to consult on training, you may want to use existing resources in the topic area. The following are a few suggestions:

Parent Training and Information Centers

Each state has at least one Parent Training and Information Center (PTI) funded by the U.S. Department of Education, to educate parents about their rights under IDEA, including information on early childhood, communication skills and family issues. Most PTIs provide training in basic rights in special education. For more information on how to reach the PTI in your state, call TAPP at the Federation for Children with Special Needs, (617)482-2915, and ask for Diana Moreno.

TAPP Focus Centers

As part of its technical assistance service, TAPP has established three centers which focus on specific aspects of serving families with special needs:

- **The Focus Center on Early Childhood** at Pilot Parents Partnerships, 2150 East Highland Ave.,#105, Pheonix, AZ 85016, (602)468-3001
- **The Focus Center on Inclusion** at the PEAK Parent Center, 6055 Lehman Dr., Colorado Springs, CO 80918, (719)531-9400
- **The Focus Center on Assistive Technology** at PLUK, 1500 North 30th, Billings, MT 59101-0298, (406)657-2055

Early Education Program for Children with Disabilities (EEPCD) Projects

This program of the U.S. Department of Education, provides funding for demonstration projects of exemplary practice, inservice training projects on special topics, and outreach projects for disseminating information about exemplary practice and special topics. Some exciting work done in the fieldcan be found in these projects. NEC*TAS has a catalogue describing each project and will help identify specific ones that can help you in your training, specifically around a special topic. For more information about EEPCD projects, call NEC*TAS at (919)962-2001.

Publications

Bibliography of Articles Recommended by Parents of Young Children for Parents of Young Children — This bibliography is a compilation of the favorite articles on training chosen by ICC parents. The bibliography is continuously updated. If you would like to suggest an article to be included, please send a copy of the article to Evelyn Hausslein at the Federation. If you would like to order a copy of the bibliography, please send $2.50 to cover the cost of mailing and handling to: Federation for Children with Special Needs, Suite 104, 95 Berkeley St., Boston, MA 02116.

Reources from NEC*TAS — This list includes publications on a wide variety of topics in early intervention, preschool special education, and technical assistance which were produced by NEC*TAS and by NEC*TAS in collaboration with other organizations. This list is available directly from NEC*TAS, 500 Nations Bank Plaza, 137 E. Franklin St.,Chapel Hil,NC 27514.

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